Needs and Resources of People With Type 2 Diabetes in Peri-urban Cochabamba, Bolivia: a People-centred Perspective

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Research

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Abstract

Background: The rising prevalence of type 2 diabetes results in a worldwide public healthcare crisis, especially in low- and middle-income countries (LMICs) with unprepared and overburdened health systems mainly focused on infectious diseases and maternal and child health. Studies regarding type 2 diabetes in LMICs describe specific interventions ignoring a comprehensive analysis of the local factors people see influential to their health. This study aims to meet this research gap by exploring what people with type 2 diabetes in Bolivia need to maintain or improve their health, how important they perceive those identified needs and to what extent these needs are met.

Methods: From March until May 2019, 33 persons with type 2 diabetes from three periurban municipalities of the department of Cochabamba participated in this study. The concept mapping methodology by Trochim, a highly structured qualitative brainstorming method, was used to generate and structure a broad range of perspectives on what the participants consider instrumental for their health.

Results: The brainstorming resulted in 156 original statements condensed into 72 conceptually different needs and resources, structured under nine conceptual clusters and four action domains. These domains illustrated with vital needs were: (1) self-management with use of plants and the possibility to measure sugar levels periodically; (2) healthcare providers with the need to trust and receive an uniform diagnose and treatment plan; (3) health system with opportune access to care and (4) community with community participation in health and safety, including removal of stray dogs.

Conclusions: This study identifies mostly contextual factors like low literacy levels, linguistic problems in care, the need to articulate people's worldview and traditional use of natural remedies with the Bolivian health system and the lack of expertise on type 2 diabetes by primary health care providers. Understanding the needs and structuring them in different areas wherein action is required serves as a foundation for the planning and evaluation of an integrated people centred care program for people with type 2 diabetes. This participative method serves as a tool to implement the often theoretical concept of integrated people centred health care in health policy and program development.

Background

The prevalence of diabetes is estimated to increase from 415 million in 2015 to 642 million by 2040, resulting in a public healthcare crisis worldwide [1]. The steep increase of primarily type 2 diabetes (T2D) can be attributed to urbanisation, changing diets and decreasing physical activity. Untreated T2D has serious physical, psychological and social consequences [2, 3]. Individuals, families and communities suffer financial hardship [2] and health systems are put under pressure [4].

Diabetes disproportionally affects low- and middle-income countries (LMICs). More than 70% of cases [5] and 80% of deaths caused by diabetes [3] are expected to take place in LMICs by 2030. Health systems based on comprehensive and community oriented primary health care (PHC) are better equipped to face the growing burden of T2D [6]. However, PHC lacks comprehensiveness in most LMICs where it is focused

on episodic treatment, especially of infectious disease and maternal and child health [7]. Concurrently, evidence from diabetes research in PHC mainly comes from high-income countries [8], making it less pertinent for LMICs [9, 10].

The few studies on T2D performed in LMICs are mainly based on isolated interventions related to training of formal or informal healthcare providers [10, 11, 12, 13], pharmacological follow-up [14] and patient education and counselling [12, 15–20]. Despite their seemingly positive short-term effects, managing chronic conditions requires a long-term strategy which involves more than performing a series of disconnected interventions [21]. To identify what works within the local context, and to promote sustainable improvement in community health, existing needs and resources of individuals with T2D, their families and communities are to be considered [22–26]. This type of healthcare design is known as 'People-Centred Health Care', defined as 'an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways' [27]. No studies were found that thoroughly explored needs and resources of people living with T2D in Bolivia.

Bolivia is a LMIC with a human development index of 0,70 in 2018, ranked as 15th of the 20 countries in Latin-America [28]. It is characterised by a high prevalence of chronic disease and a weak PHC system [29]. The prevalence of T2D in the main urban regions was estimated at around 7,2% in 2001, with no later epidemiological studies available [30]. The main goal of this study was to identify needs and resources of people living with T2D in peri-urban Cochabamba.

Methods

The objective of this study was to obtain an extensive set of perspectives from people living with T2D from diverse socio-economic backgrounds in Cochabamba, Bolivia on what is needed to live with T2D and structure these perspectives in a comprehensive framework.

Participants

A total of 33 people with T2D were recruited from March until May 2019 in Cochabamba, Bolivia. A convenience sample in three peri-urban regions of Cochabamba was used. All participants were over 18, had T2D and spoke Spanish as a first or second language. 14 people took part in the generation of statements related to needs and resources as well as in the valorisation of these statements. 19 additional participants took part in the rating phase, resulting in 33 people participating in this study.

Recruitment procedure

The greater the variety of the participants, the richer the outcome of the concept map. People with diverse socio-economic backgrounds were selected to participate in this study through different recruitment strategies. First, nine participants were recruited by joining outreaches of a local primary health centre in the peri-urban part of the municipality of Sacaba. These participants were known by the public healthcare

centre and were asked to participate by their healthcare providers. Second, the researcher encountered five additional participants in the same peri-urban zone through direct community contact. These latter participants were formerly diagnosed with T2D, but unknown by the local public health centre. The remaining 19 participants were recruited by joining an outreach of a general practitioner working in the peri-urban part of the municipality of Quillacollo, and in the rural municipality of Punata. The general practitioner asked these 19 persons to participate in this study. All participants were diagnosed with T2D prior to this study, and signed an informed consent.

Data collection

Design

The concept mapping methodology by Trochim was selected for its ability to create a comprehensive framework for evaluation and planning of diabetes management in the communities under study. This participatory method is well suited to deal with complex human systems in public health [31]. It is inductive, based on major ideas of participants that are interrelated to design a well-structured concept map which provides feedback to the system under study. The methodology consists of a multi-step process as seen in Fig. 1. Firstly, the focus of brainstorming and ratings is defined. Secondly, participants generate a set of statements during a brainstorming session. Thirdly, these statements are structured during a rating and sorting process and fourthly they are represented in a concept map, visualising the statements, their ratings and how they are interrelated [32].

Figure 1. The Concept Mapping Process (Adapted from Leyns et al., 2018) [27].

Step 1: Preparation The ‘seeding question’, or focus of the brainstorming, was constructed aiming for an optimal width and depth of desired data. This focus must be comprehensible and unambiguous for all participants. The seeding question in this study was developed by the project team and validated linguistically and culturally by a general practitioner and a group of eight people with T2D in a community of Sacaba resulting in: ‘Thinking as broadly as possible, what is needed to maintain or improve your health or the health of other people with diabetes in your community?’. Subsequently, the rating focus was defined, considering the kind of information desired. A Likert-scale from one to five was selected to assess the ‘importance’ and ‘presence’ of each statement [31] with answer categories ranging from 1 = Not important to 5 = Essential, and 1 = Not/never present to 5 = Very/always present. Apart from the seeding question, the selection of participants was a fundamental step in the concept mapping.

Step 2: Generation of statements During the first concept mapping group session participants were asked individually to think of statements in response to the abovementioned seeding question. They shared their statements one by one within a nominal group process, guaranteeing maximum equality of input [33]. Each statement was rephrased where necessary to improve understanding but was accepted without discussing its validity or relevance for other participants [31]. Very few statements were generated. The project team attributed this to low literacy levels and culturally imbedded apprehension of the participants to express themselves. Therefor the method of data collection was adapted and respondents were visited

individually at home instead of bringing them together in group sessions. Home visits started with a short discussion of the seeding question, giving the participant the possibility to reach full understanding. The participant was encouraged to think broadly in order to generate as many statements as they could think of in response to the seeding question. After generation of own statements, statements obtained at previous home visits were tested for understanding. 156 semantically different statements were formulated during 14 home visits. These were analysed and reduced to 72 different conceptual ideas by two independent researchers.

Step 3: Structuring of statements The importance, presence and sense of interconnectedness of the generated statements was determined through a rating and sorting process [34]. Regarding the rating, the 14 participants who generated the statements were visited a second time to perform the rating of each statement on importance (1–5) and presence (1–5) With the following questions: "How important is this need for you or other people with diabetes?' (Importance) and 'Is this need fulfilled for you and for other people with diabetes?' (Presence). 19 additional people with T2D participated in this rating-process. Because of low literacy levels, the ratings were done verbally, assisted by a visual representation of the rating scores. The sorting was performed by a registered nurse (researcher), a general practitioner (researcher), a political scientist and a social worker. They received the 72 statements on individual numbered cards and grouped them into piles 'in a way that made sense to them' [31]. Each person in the sorting process grouped the cards several times, in several ways that made sense to them.

Analysis

Step 4: Representation of the statements The 72 statements, including their rating- and sorting-data were uploaded in the free open-source concept mapping software, implemented in R [34]. Average rating scores on importance and presence for each individual statement were calculated. Subsequently, the software applied a sequence of algorithms to the sorting data, starting with the construction of a square binary matrix for each sorting task, with as many rows and columns as there were statements, to identify which statements were sorted together in piles [31]. All these matrices were added up to obtain a combined group similarity matrix. A high value in this matrix meant a high level of conceptual similarity between two statements. This resulted in a concept map with 72 different dots (in a point map), representing the statements, and 10 'groups of dots', or clusters (in a cluster map). Average rating scores on importance and presence were computed for each cluster based on the ratings of the statements within. This process allowed the identification of major ideas and concepts and their interrelatedness [32].

Step 5: Interpretation of the map In the original methodology participants are asked to read the statements within the computed clusters individually and form a phrase or word to describe these clusters until obtaining a group consensus on cluster names, removing erroneous clustered statements, identifying relations between clusters and grouping clusters into meaningful domains [32]. In this research, the participants did not participate in this step due to low literacy levels. The four previously mentioned persons who participated in the sorting process, named the computed clusters, moved erroneous clustered statements and identified meaningful domains. The result was the concept map as illustrated in Fig. 2.

Figure 2. The concept map with 72 conceptually different statements represented by small black numbers, nine clusters indicated by larger white numbers and four action domains named with capital letters. Statements in a red circle are seeming anomalies that were moved to another cluster.

Results

Socio-demographic data 33 individuals with T2D from three peri-urban municipalities of the city of Cochabamba participated in this study. Participants were primarily women (76%), over 50 years old (84%) and did not complete secondary education (67%). Most of the participants worked either in the informal sector (40%) or were unemployed (51%). These and other socio-demographic data are shown in Table 1.

Table 1
Socio-demographic data participants

	n (%)
Sex	
Male	8 (24%)
Female	25 (76%)
Age	
41–60 years	17 (52%)
61–80 years	16 (48%)
Spoken language	
Spanish	33
Quechua	29
Aymara	2
Max. level of education	
No education	9 (27%)
Primary education	13 (40%)
Secondary education	9 (27%)
College/ university	2 (6%)
Occupation	
Working in informal sector	14 (42%)
Working in formal sector	2 (6%)
Domestic work	11 (34%)
Retired	6 (18%)
Pharmacological therapy	
Oral glucose lowering drugs	11 (33%)
Oral glucose lowering drugs + insulin	11 (33%)
Insulin	9 (28%)
None	2 (6%)
Number of years diagnosed	
1–10	13 (39%)

	n (%)
> 10	20 (61%)
Living situation	4 (12%)
Alone	29 (88%)
With spouse/family	

Footnote: n = absolute number

Identified domains and clustered structuring needs of people with T2D

In total, participants generated 156 original statements that were summarized in 72 conceptually different needs. These needs were rated by the participants and sorted afterwards, resulting in a concept map with 10 different clusters as shown in Fig. 2. Revising the clusters, some statements were moved to more appropriate clusters, improving their coherence, resulting in the complete redistribution of the 10th cluster. The remaining nine clusters were grouped in four overarching domains. The four domains with their underlying clusters and corresponding importance- and presence-scores are shown in Table 2. Rating scores are shown with an accuracy of two decimals, while in the written results, ratings were rounded. A 3,33 on importance for example, was rounded to 3, seen as ‘important’, while a 3,66 was considered ‘very important’. In the results, the different clusters are indicated by a number between brackets, which is also the cluster number on the concept map.

Table 2
Domains and clusters to achieve people-centred care for type 2 diabetes in Cochabamba, Bolivia

	Importance	Presence
1. SELF-MANAGEMENT (14)		
1. **Self-Management Practices (6)**	**4,55**	**3,76**
Consuming plants, herbs and other natural remedies	4,58	4,03
Maintaining a register for daily follow up of foods, symptoms, blood sugar…	4,32	2,84
2. **Knowledge on Diabetes Management & Health literacy (8)**	**4,74**	**3,23**
Having the possibility to measure the sugar level periodically	4,91	3,22
Knowing the different types of medication and its' side-effects	4,61	2,96
2. HEALTHCARE PROVIDERS (18)		
3. **Social and Professional Competences (12)**	**4,72**	**2,71**
Healthcare personnel reduces fear of the condition through explaining the condition (psychological assistance)	4,78	2,27
A physician who knows the medical and social history of the patient	4,68	3,20
4. **Patient Education (6)**	**4,80**	**3,00**
Healthcare personnel teaching the patient about what is diabetes	4,76	2,81
Having information and orientation on healthy foods during medical attention	4,86	2,83
3. HEALTH SYSTEM (25)		
5. **Healthcare Resources and Health Insurance (11)**	**4,70**	**2,82**
Having hospitals close by that accept you when you need urgent medical care	4,94	3,29
Having enough physicians and medical material in the region	4,87	2,87
6. **Access to healthcare services (8)**	**4,77**	**2,45**
Waiting little time in line for medical assistance in healthcare facilities	4,87	1,97
Having access to consults with a nutritionist	4,68	1,47
7. **Home and community care (6)**	**4,20**	**1,83**
Community and/ or home-visits of healthcare personnel	4,66	2,13
Having first aid or a physician on duty in the community	4,88	1,69
4. COMMUNITY (15)		

	Importance	Presence
8. **Family and community participation (6)**	**4,70**	**2,07**
A community council engaged in enhancing health of its' inhabitants	4,69	2,03
People with knowledge on good nutrition and foods in the community who teach how to eat in a healthy way	4,69	1,53
9. **Social and Environmental determinants of Health (9)**	**4,90**	**2,85**
Having good provision of healthy foods in the neighbourhood	4,94	2,88
Having streets without dogs so you can walk and exercise in a safe way	4,75	1,88

Four domains containing nine clusters that group 72 needs for people centred diabetes care. For each cluster two needs are presented.

The number between brackets refers to the number of statements in each domain or cluster. The Bold numbers are the means of all the statements in each cluster.

Self-management

The needs related to self-management were grouped in two clusters: 'Self-management Practices' and 'Knowledge on Diabetes Management & Health literacy'.

The self-management practices (1) used in the community were perceived as essential (Importance-average = 4,55) to live with T2D on cluster-level. The statements with the highest importance and presence scores were 'having faith in God or religion in general' (Importance = 5,00; presence = 4,85) and 'taking indigenous plants, herbs and other natural remedies' (Importance = 4,58; presence = 4,03).

The second cluster on Knowledge on Diabetes Management & Health literacy (2), was considered as essential (Importance-average = 4,74) but only sometimes present (Presence-average = 3,23). Knowledge on glucose-levels (Presence = 3,19) and different types of medication and their side-effects (Presence = 2.96) was particularly low. Remarkable was the generalized lack of knowledge on how to access the healthcare system and obtain free services and medication (Presence = 1,91).

Healthcare Providers

The clusters related to the Healthcare providers were 'Social and Professional Competences' and 'Patient Education'.

Social and professional competences (3) of healthcare providers were rated on cluster-level as essential (Importance-average = 4,74), yet only sometimes present (Presence-average = 2,84), like the need to trust the health provider (Importance = 4,40; Presence = 3,36). Healthcare providers failed in reducing fear and

distress (Presence = 2,27) and were barely considered to be aware of family-problems (Presence = 1,63). Furthermore, health providers' capacity to communicate in the local indigenous language was highly appreciated, yet often absent (Presence = 2,67). Great importance was attached to monthly check-ups, yet, these only occasionally took place (Presence = 3,15). Furthermore, participants expressed an urgent need for uniformity of diagnoses and treatment plans by different physicians for the same health problem (Importance = 5; Presence = 2,11).

Receiving education (4) from healthcare providers was rated as essential (Importance-average = 4,76), however only sometimes available (presence-average = 2,75). Healthcare providers seldom educated patients on T2D (Presence = 2,81), nor on medication use and alimentation (Presence = 2,50 – 2,83). Although highly valued, the need to educate family-members was rarely fulfilled (Presence = 2,50). It was remarkable that, although it was rated as essential, education on commonly used plants and herbs was nearly inexistent (Presence = 1,78).

Health System

The clusters 'Healthcare Resources and Health insurance', 'Access to healthcare services' and 'Home and community care' were grouped under the domain health system.

Aspects related to healthcare resources and health insurance (5) were rated as essential (Importance-average = 4,70), but only occasionally present (Presence-average = 2,82). Participants experienced a shortage of physicians (Presence = 2,87), medical supplies (Presence = 2,87) and medications such as insulin (Presence = 2,67). Affordable transportation to healthcare facilities was highly valued and generally available (presence = 3,88), but transportation for urgent medical assistance, such as an ambulances was practically unavailable (presence = 1,84). Health insurance was rated as very important (Importance = 4,32), however rarely perceived as available (Presence = 1,66).

The cluster, access to healthcare services (6), was rated as essential (Importance-average = 4,77), however needs were mostly unfulfilled (Presence-average = 2,45). Participants experienced long waiting times (Presence = 1,97) and a lack of guidance by their general practitioner in finding access to specialist care (Presence = 2,30). Moreover, even though perceived as essential, availability (Presence = 2,96) and affordability (Presence = 2,38) of specialist care in-hospital was perceived as deficient. Access to urgent medical care was particularly lacking (Presence = 2,23).

Home and community care (7) was rated as very important (Importance-average = 4,20) though inadequate (Presence-average = 1,83). A first aid post or a physician on duty (Importance = 4,69; Presence = 2,30) and community or home-visits by healthcare professionals were highly appreciated but practically unavailable (Importance = 4,66; Presence = 2,13). Paramedical care such as physiotherapy (Presence = 1,28) and social services (Presence = 1,26) were desired, but non-existent in the community.

Community

The importance of community was described in two clusters: ‘Family and community participation’ and ‘Social and Environmental Determinants of Health’.

Family and community participation (8) was rated as essential (Importance-average = 4,70) but barely present (Presence-average = 2,07). Experienced support by fellow community members (presence = 2,06) and engagement of the community council in enhancing people’s health was very weak (Presence = 2,03). Furthermore, activities and gatherings for the elderly in the community (Presence = 1,63) and periodical meetings with people with diabetes and their families (Presence = 1,59) were requested but unavailable.

Needs within the cluster social and environmental determinants of health (9) were rated as essential (Importance-average = 4,90), yet only sometimes fulfilled (Presence-average = 2,85). At the one hand, most participants indicated having an adequate supply of basic utilities such as water and electricity (Presence = 4,41). On the other hand,

availability of asphalted well-lit streets (presence = 2,91) and healthy foods in the neighbourhood was poor (Presence = 2,88). There was an urgent need for security in the community (presence = 2,28), which was impeded partially due to the presence of stray dogs.

Discussion

The main objective of this study was to identify what people with T2D in Cochabamba, Bolivia needed to maintain or improve their health, and what resources they relied on, in order to develop contextualised people-centred diabetes care. A broad range of needs were identified, but many remained unmet. These needs were associated with four action domains: Self-management, Healthcare providers, Health system and Community.

Relating to *self-management*, the design of a self-management plan must be in line with existing practices, knowledge and literacy levels [35–38]. Participants confirmed the importance of considering existing knowledge and supportive practices as fundaments for their self-management. One example of an important supportive practice was the reliance on religion with proven effects on glucose-levels, coping and self-management [39, 40]. The same holds for the use of plants and herbs with potential of improving diabetes management such as ginseng [41], ginger [42] and aloe vera. Aloe vera has shown to reduce blood glucose levels, decrease blood lipids and promote healing of wounds such as venous ulcers [43]. Furthermore, lesser known plants were used by the study population, such as yacon, a root originated from the Andes known for its’ hypoglycaemic properties, confirmed in several clinical trials [44, 45]. Reliance on these plants and herbs is interwoven with indigenous culture and must be better articulated with the Bolivian healthcare system that enacted a law on inclusion of traditional medicine [46, 47]. Besides the reliance on traditional medicine, participants experienced a lack of essential knowledge on T2D, partly due to low literacy levels. Less than one out of three participants finished secondary education urging for a contextualised strategy to improve health literacy which is essential for access to health care, glycaemic control, prevention of retinopathy, and self-perceived health [48, 49].

Collaborative care, wherein expertise of patients, as described in the previous paragraph, and expertise of *Healthcare providers* is combined, was not reflected in this study [21]. Expertise of healthcare providers at the primary healthcare level seemed inadequate, leaving patients with unfulfilled educational needs. However, support by healthcare professionals is pivotal in diabetes self-management education [23], leading to improved HbA1c-levels [50–52], self-efficacy and empowerment [53], healthy coping [54] and reduced diabetes-related distress [52]. Moreover, self-management education was impeded due to poor communication skills of healthcare providers through both linguistic problems, failure to communicate in the indigenous language [55], and the lack of a trustful continuous relationship. The latter has been shown in literature to be a condition for effective communication and interpersonal care [56] that facilitates health promotion [57–59] and metabolic control [60, 61].

The *Health system* was the third action domain with the highest number of needs. In March 2019, the 'Sistema Unico de Salud' was introduced, a universal health system intended to provide free basic healthcare including periodic controls of glucose-levels, education on diet and exercise in PHC, pharmacological treatment with glibenclamide and metformin and yearly check-ups with an ophthalmologist [62]. Before this healthcare reform, free basic healthcare was limited to people over 60 [63]. Despite the prior and current universal health system, most needs concerning the health system remained unmet. Access to basic health services including physicians, medical supplies and essential medications were lacking. Concurrently, low literacy levels within the study population added to difficulties in understanding how to get administrative access to the public healthcare system [59]. This presumably generates care seeking in the private healthcare system, putting a strain on household budgets due to higher out-of-pocket expenditures [64]. Reasons for this flee to private healthcare in previous studies, as well as reflected in this study, were better access, shorter waiting times, better confidentiality, distrust in government institutions and better accordance to people's needs in general [65].

Community, the fourth action domain, comprised needs relating to the physical and social environment of the individual. Regarding family and community participation, family-support was generally experienced, but support by fellow-community members was lacking despite the positive effect of community-support on diabetes management [66, 67]. Community members and local authorities were perceived as insufficiently engaged in healthcare, despite a Bolivian law that obliges community participation in local healthcare design [62]. As such, opportunities for the community and healthcare team to co-create relevant actions on health and its determinants were missed [68]. Beside these participative needs, several needs were mentioned regarding the physical living environment, and confirmed by existing literature such as the impact of green and recreational space [69, 70], traffic noise [71, 72] and neighbourhood safety. Certain aspects such as the lack of healthy foods and the presence of stray dogs, impairing the possibility to exercise, were prominently mentioned. People-centred, as well as community oriented PHC can, with their focus on social and physical health determinants, serve as a model to consider the environment and include community members in healthcare design [68, 73].

This research adds to an increasing body of evidence on needs and experiences of people with T2D [74–78], of which most studies were performed in HICs. Results of this research coincided partially with

previous research such as the need for support from healthcare professionals [74, 76–85] and the role of family and social support in diabetes management [74, 76–78, 80]. Other results varied from previous research. First, contextualised information and education on T2D was almost absent and urgently needed [86, 87]. Causative factors for this lack of education could be the substandard training of health providers on T2D at the primary health care level and the heavy burden to educate people with low (health) literacy from different socio-cultural backgrounds in a low-resource setting. Second, many experienced distrust in healthcare institutions, resulting in non-adherence to therapies or lifestyle advice and poor self-management [88, 89]. Western medicine is frequently felt as imposed, and poorly culturally embedded [90]. Inclusion of traditionally widely used plants and herbs in healthcare, and communication in the local indigenous languages could promote trust. Third, the lack of supplies and medications such as insulin that are readily available in HICs [91].

This study led to a comprehensive exploration of needs of people living with T2D in a LMIC, which is unseen in previous studies. Because of the very broad and positively formulated seeding question: 'Thinking as broadly as possible, what is needed to maintain or improve your health or the health of other people with type 2 diabetes in your community?', many health needs were identified such as 'having faith in God or religion', going further than individual needs mentioned in the doctor's office. As such, wider community needs have been identified, which is pivotal for planning and evaluation of health services. Healthcare planning based on these results goes further than traditional planning based on ratios of non communicable diseases by understanding the roots of health problems [92]. The WHO (2001) affirmed the necessity of this community health needs assessment in the planning and delivery of effective care, ensuring fair allocation of scarce resources [93].

It is important to note that this research had shortcomings. Because of the time constraints, the sample size of this study was relatively small and convenience sampling was used. This hindered in making analyses based on, for example, socio-economic status, gender, language, insurance scheme and time of diagnose. Furthermore, women (75%) were overrepresented in this research although experiences of men and women with T2D are shown to be different [92]. In addition, the perspective of people who only speak local indigenous languages was not explored.

Further studies with the concept mapping methodology including all relevant stakeholders are recommended in order to get a comprehensive understanding of what is needed for optimal diabetes management in Bolivia, and LMICs in general. An interesting element can be a better understanding on commonly used plants and herbs in the lives of people living with T2D in order to include their use within the actual healthcare system. Strengthening general health literacy is another underexplored topic in Bolivia and its' understanding can be instrumental in the design of health education adapted to the diverse socio-cultural population groups.

Conclusion

This exploratory study revealed important needs and resources of people living with T2D in peri-urban Cochabamba, Bolivia, like the urgent need to acquire knowledge and capacities to manage this condition.

These needs were hampered by low literacy levels and the lack of continuous qualitative support by healthcare professionals prepared to deal with T2D in a socio-cultural and linguistic sensitive way. Modern medicine was not always accepted due to a lack of articulation with people's prior experiences, worldviews and commonly used natural remedies. In addition, essential healthcare, including medical supplies and medications, were often unavailable. The results of this study grant an opportunity to include the voice of people with T2D in the design of an inclusive, efficient and acceptable diabetes program including community-based health promotion and support activities. Taking people's needs, resources, health literacy levels and social and cultural influences into account is essential to make diabetes care relevant and people centred. Integrated interventions in all the proposed action domains are needed for the development of a comprehensive approach to diabetes care, wherein caregiver, care-receivers and their community become partners in improving the health of their community. Beyond the bounds of this research the results encourage critical thinking and debate on health care organisation in general.

Abbreviations

T2D
Type 2 diabetes; LMICs:low- and middle-income countries; HICs:High income countries; PHC:Primary health care; WHO:World Health Organization

Declarations

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The datasets used and/or analyzed during the current study can be made available from the corresponding author on reasonable request.

Authors' contributions:

CL and NC contributed to project conception and design, data collection, coding and interpretation of data, literature review and analysis, and drafted the manuscript. SW contributed to project conception and design, and critically revised the manuscript. AVH provided project supervision, contributed to project

conception and design, and critically revised the manuscript. All authors read and approved the final manuscript.

Ethics approval and consent to participate:

All activities were approved by the ethical board of the Ghent University Hospital (Belgian registration number: B670201939443). All study participants were informed and signed an informed consent form.

Consent for publication:

not applicable

Competing interests:

The authors declare they have no competing interests.

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Figures

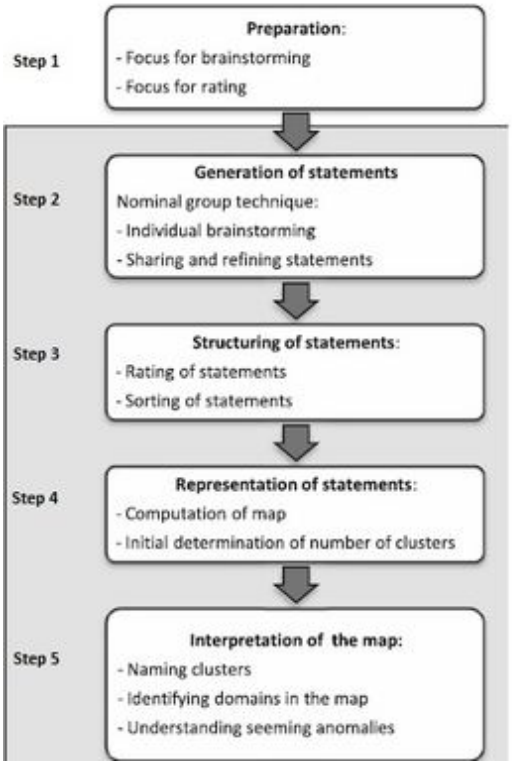

Figure 1

The Concept Mapping Process (Adapted from Leyns et al., 2018) [27].

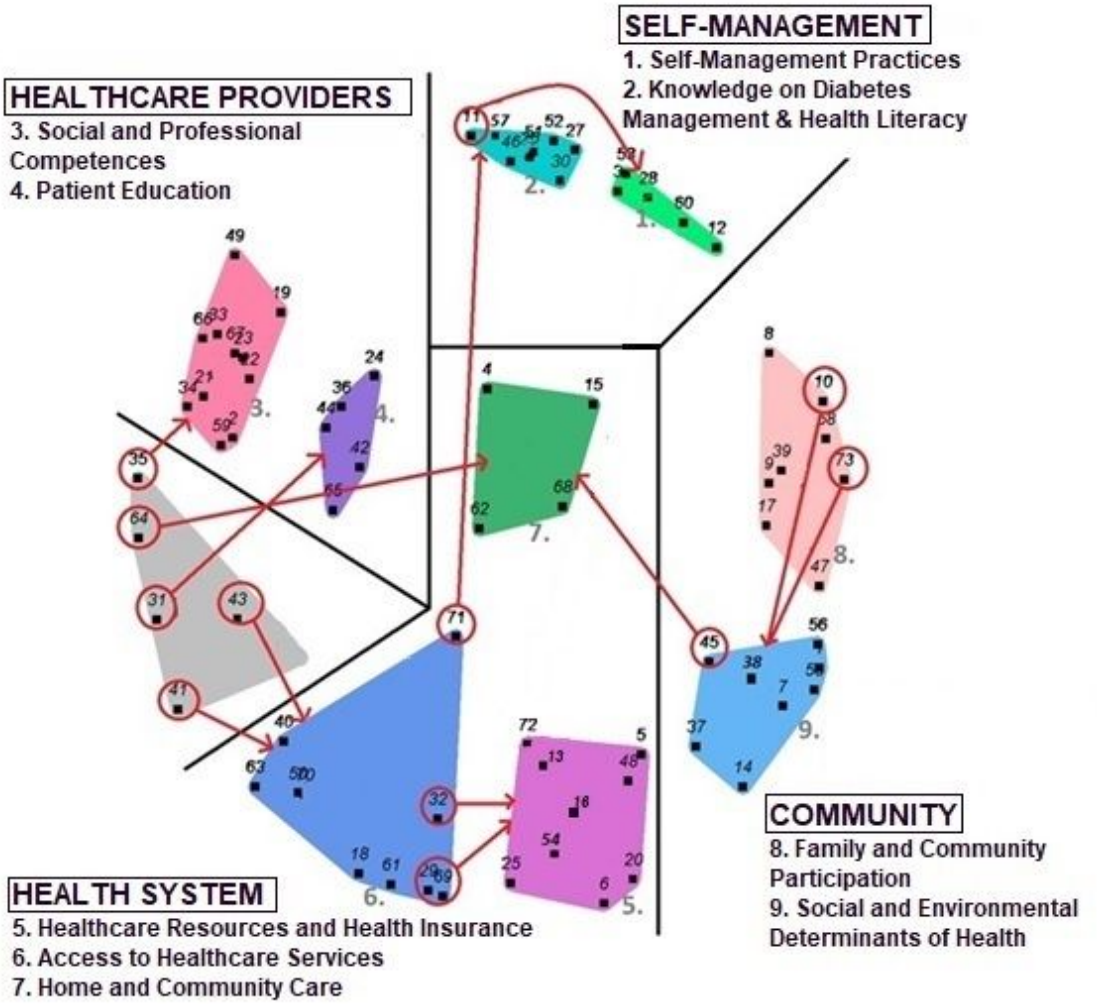

Figure 2

The concept map with 72 conceptually different statements represented by small black numbers, nine clusters indicated by larger white numbers and four action domains named with capital letters. Statements in a red circle are seeming anomalies that were moved to another cluster.